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RESEARCH

SOCIAL SUPPORT IN THE CONTEXT OF POVERTY: A STUDY OF THE ELDERLY WITH COGNITIVE IMPAIRMENTS AND THEIR FAMILY CAREGIVERS

APOIO SOCIAL EM CONTEXTO DE POBREZA: ESTUDANDO IDOSOS COM ALTERAÇÕES COGNITIVAS E SEUS CUIDADORES FAMILIARES

APOYO SOCIAL EN EL CONTEXTO DE POBREZA: UN ESTUDIO ACERCA DE ANCIANOS CON ALTERACIONES COGNITIVAS Y SUS CUIDADORES FAMILIARES

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ABSTRACT

**Objective:** To describe the structure and function of social support networks of elderly people with cognitive impairments who reside in the context of high social vulnerability, and their family caregivers. **Method:** The subjects were 33 elderly enrolled in Family Health Units that showed performance on the Mini Mental State Examination below the cutoff score in a previous study, and their 33 caregivers. We applied the Mini-Mental State Examination and Diagram Escort. All ethical guidelines were followed. **Results:** Both the elderly and caregivers relate social networks with similar characteristics. Caregivers, however, provide more support than the elderly. In both cases networks are numerous, however, few members providing or receiving support. **Conclusion:** The use of social networks as a therapeutic resource must be designed to establish the plan of care to the elderly. **Descriptors:** Aged, Social Support, Caregivers.

RESUMO

**Objetivo:** Descrever a estrutura e função das redes de apoio social de idosos com alterações cognitivas que residem em contexto de alta vulnerabilidade social, e de seus cuidadores familiares. **Método:** Os sujeitos foram 33 idosos cadastrados em Unidades de Saúde da Família que apresentaram desempenho no Mini Exame do Estado Mental abaixo da nota de corte em estudo anterior, e seus 33 cuidadores. Aplicou-se o Mini Exame do Estado Mental e o Diagrama de Escolta. Todos os cuidados éticos foram observados. **Resultados:** Tanto os idosos, quanto os cuidadores referem redes sociais com características semelhantes. Os cuidadores, no entanto, fornecem mais apoio do que os idosos. Em ambos os casos as redes são numerosas, porém, poucos integrantes oferecem ou recebem apoio. **Conclusão:** A utilização das redes sociais como recurso terapêutico devem ser pensadas no estabelecimento do plano de cuidado ao idoso. **Descritores:** Idoso, Apoio Social, Cuidadores.

RESUMEN

**Objetivo:** Describir la estructura y función de las redes de apoyo social de personas mayores con deterioro cognitivo que residen en contexto de alta vulnerabilidad social, y sus cuidadores familiares. **Método:** Los sujetos fueron 33 adultos mayores inscritos en Centros de Salud Familiar que mostraron el rendimiento en el Mini Examen del Estado Mental por debajo del punto de corte en un estudio anterior, y sus 33 cuidadores. Se aplicó el Mini Examen del Estado Mental y Diagrama de Escolta. Todas las recomendaciones éticas fueron observadas. **Resultados:** Tanto las personas mayores y los cuidadores se refieren las redes sociales con características similares. Los cuidadores, sin embargo, ofrecer más apoyo a los ancianos. En ambos casos las redes son numerosas, sin embargo, pocos miembros suministrar o recibir apoyo. **Conclusión:** El uso de las redes sociales como un recurso terapéutico debe ser diseñado para establecer el plan de atención a los ancianos. **Descriptor:** Anciano, Apoyo Social, Cuidadores.

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## INTRODUCTION

The growth of the elderly population has been fairly rapid, coupled with the aging, the situation of chronicity and the greater life expectancy contribute to the increase of Brazilian elderly and dependents requiring care.<sup>1</sup>

Traditionally in Brazil, the care given to the most dependent elderly is held by the family. However, changes in family models, associated with an increased population segment that demands for care, have brought a strong impact for Brazilian families both emotionally and financially<sup>2</sup>. Moreover, changes in patterns of mortality and fertility have brought major changes in the architecture of families (increased life expectancy and fewer children per couple), which may influence the way they care for their elderly.<sup>3</sup>

The main constraints regarding the care for an elderly person in family context are related to financial, personal and social aspects. When situations of dependency arise, there is a need for family adaptation and reorganization, which is reflected in the adjustment of family roles defined over time and the way each member interacts with the others. At the same time, the readjustment in family structure depends on how the changes and events have originated, and the resources available to deal with such modifications.<sup>4</sup>

Besides the aspects of family dynamics and organization, taking care of a dependent elderly demands economic resources, time and personal organization, which added to other social demands, generates heavy workloads and can have negative consequences for the caregiver and the care given to the elderly. Such consequences may be, for example, depression, dissatisfaction towards life, stress, fatigue, money problems, loneliness, guilt, anger, sadness, fatigue, anxiety and despair.<sup>4</sup>

R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3787-94

An alternative to these situations is the existence of social support networks within which family members find help to their needs in everyday situations and crisis. Thus, caregivers who have multiple sources of social support and effective problem dealing strategies experience greater wellbeing and provide better quality care to their elderly relatives.<sup>4</sup>

Social support network is the web of social relationships which everyone holds, including close relationships (such as family and close friends) and more formal relationships (other individuals and groups). Even though it is well studied, there is no consensus among researchers about the concept of social support. This concept is part of several theoretical frameworks and models of practice. It is necessary to have an agreement among the object of study, theoretical framework and method to be developed, either quantitative or qualitative. We can explain (among various points of view) "social support" to be a function of social networks. It is considered the main function and also the sponsor in the construction of networks.<sup>5</sup>

Not only does social relationships promote the caregivers' health, it also contributes to the improvement in the elderly health. Social support can both protect the elderly from the pathogenic effects of stressful events and also positively affect the health of people by providing resources (financial assistance, material resources, information), better access to health care and regulation of lifestyle. Through social support networks, the feeling of being loved and valued, belonging to communication groups and reciprocal obligations, avoid the elderly of that isolation feeling and also anonymity common to this age group.<sup>6</sup>

Considering the uniqueness and complexity of the relationship between caregiver and elderly, and recognizing that social support has been shown to mediate the stress associated with care,

it is very important to identify how social support networks work for seniors and their caregivers in order to use them as a therapeutic resource in the elderly care plan<sup>7</sup>. This study, therefore, aims to describe the structure and function of social support networks for the elderly with cognitive impairments who are in the context of high social vulnerability, and their family caregivers.

METHODOLOGY

This is a transversal and descriptive study, based on the quantitative research method. The research was conducted in the municipality of São Carlos, located in the central region of São Paulo. Data were collected in the family caregivers' houses of elderly living in poverty. To characterize the context of 'poverty' we used the Index of Social Vulnerability (IPVS).<sup>8</sup>

IPVS classifies census sectors in the state of São Paulo according to the levels of social vulnerability of the population based on socioeconomic and demographic characteristics of the inhabitants throughout the state, these municipalities are then compared and analysed. In São Carlos there are six groups: no vulnerability, very low vulnerability, low vulnerability, average vulnerability, high vulnerability and very high vulnerability. Units were chosen based on the classification by IPVS as 'high' (IPVS 5) and 'very high' (IPVS 6) social vulnerability.<sup>8</sup>

Inclusion criteria for the elderly in the study were: be 60 years or older, be enrolled in Family Health Units with IPVS 5 or 6, showing results on the Mini Mental State Examination score below average<sup>9</sup> (according to education degree) in a previous study, show no severe language impairments or understanding and have a family caregiver. Both the elderly and their caregiver signed a consent form.

197 out of 370 seniors enrolled in the two units of study had already been evaluated in a R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3787-94

study in 2007. 85 had a result below the MMSE cutoff score, which made up the population of this study. Dropping the losses due to death and migration of domicile, this study evaluated 46 elderly. Considering the criteria for eligibility, 13 elderly were excluded after evaluation showed results above the cutoff score on the MMSE. The final population, therefore, was composed of 66 individuals, 33 were elderly and their respective 33 caregivers.

Individual domiciliary interviews were held, previously scheduled to follow a previously elaborated plan. The interviews took place after reading and signing the consent form. The instruments used in the elderly and their caregivers were: socio-demographic instrument of comparison and the Escort Diagram to assess social support network. The elderly still answered the Mini Mental State Examination for cognitive assessment.

The Escort Diagram was adapted to the elderly population in Brazil in 2008<sup>10</sup>. The design of the diagram is based in three concentric and hierarchical circles, with the participant being represented in the middle. There, we place the people who are close and important to the elderly. The diagram is presented in a framework made of felt (100cm x 60cm), drawn in a color easily seen. Along with the diagram, there are a series of dolls of different sizes, shapes and colors (blue for boys and pink for girls).

On the back of the dolls, we put a piece of velcro so it can be posted on the felt. We present the instrument in a fun and interactive way, which facilitates its application. The participant is asked to think about the people who are important in his life and with which he maintains different levels of proximity. The respondents are asked to think about "those people you feel so close it would be hard to imagine life without them." These people should be placed in the inner circle of the diagram.

The same procedure is done for completing the intermediate circle, to be "those people who you do not feel too close, but still are very important to you." Finally, for the outer circle, the participant may think about "those people that you have not mentioned, but who you feel close and that you believe are important enough so that it should be placed in your network." On a separate sheet of paper, the applicators write down in the illustrated diagram, the name and location where each person was entered by the participant in their network.

This procedure may be done as the participant includes new members in his diagram. This is a key step so that questions about the structure and function of the network can be properly completed. This first stage of the diagram implementation is intended to collect information on the structural characteristics of the respondent social support network. The second stage of the diagram application aims to obtain the structural and functional aspects of the support network. This step starts with a series of questions on the first ten people listed by the respondent in his network.

The key points about the network's structure are: name of the people included in the network, age, genre, the circle in which the person named was positioned, relationship with the participant (spouse, child, grandchild, brother, other relatives, or friend), time elapsed since the relationship began, frequency of contact and how far the houses are (the respondent's and the people in his network). The contact frequency is evaluated according to the following scale: 1 - irregularly, 2 -annually, 3-monthly, 4 - and 5 weekly - daily or live together. This scale should be verbally introduced to the participant and he then will indicate which option is the best. The distance among the houses is measured in hours considering a car as a means of transportation. Thus, it begins with an hour (60 minutes) but the R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3787-94

travel time may be shorter (eg, 30 minutes). The functional characteristics of the support network are evaluated according to six types of supporting relationship, given and received by the respondent. These relationships are: (1) reveal important things, (2) to be soothed and stimulated in times of uncertainty, (3) be respected, (4) be careful in situations of illness, (5) talk when sad, nervous or depressed, and (6) talk about their own health. Regarding these functional issues, we ask the participant to look at their chart and to indicate those people from whom he/she receives each type of support and to whom he gives each of those.<sup>11</sup> The data was analyzed using descriptive statistics, and the recommendations according to Resolution 196/96 regulated by the National Council of Health<sup>12</sup> were fully observed. The study began after being approved by the Ethics Committee on Human Research of UFSCar (Opinion 018/2011), and interviews were conducted after the agreement of the subject.

RESULTS AND DISCUSSION

We interviewed 66 individuals: 33 individuals were elderly and the other 33 individuals were the caregivers of these elderlies.

The elderly reported a total of 470 members in their social networks, resulting in networks with an average of 12.4 people. The innermost circle, where closer people are placed to the interviewee (people without whom it would be difficult to live), showed the largest number of members (350), with an average of 9.2 people in this circle, in the network of each elderly. Still considering the closest people to the elderly, in the first circle there was a predominance of females (54%), and people aged between 31 and 40 years (24.3%). Most of these people were the elderly's children (45.7%), followed by grandchildren (21.4%).



In the middle circle, where the elderly placed the people who are not so close, but still are very important to him, they placed 116 people, with an average of three individuals in this circle on each network. There was a predominance of females (54.3%), and people aged 60 years or older (23.3%). Most of these people (34.5%) are classified as another family member who is not the spouse, children or grandchildren.

In the third round, the farthest related to the respondent, they placed those people who had not been mentioned, but they are close and important enough to integrate the social network of the elderly. Of a total of 33 seniors, only three included people in this circle. These seniors mentioned a total of four people in the outer circle, resulting in an average of 0.1 people in this circle on each network. All these people were women, three were aged between 51 and 60 years, and one person aged between 31 and 40 years. Three were mentioned as friends and as another family member who is not the spouse, children or grandchildren.

With respect to the caregivers of the elderly, the data show that most caregivers are women (75.8%), aged between 70 and 79 years (21.2%), schooling 4-7 years (27, 3 ), married or cohabiting (57.6%), whites (45.4%) and Catholics (51.5%). Most caregivers live with four or six people in the house (36.4%).

Regarding the network structure of social support, family caregivers reported a total of 385 members, with an average of 11.6 people per network. The inner circle of the diagram showed the highest number of 235 members, with an average of 7.12 people in this circle. In the second circle, 103 people were mentioned, with an average of 3.12 people on the network. In the third round were mentioned 47 individuals, an average of 1.42 people per circle.

Regarding the first circle, there was a predominance of females (54.47%), and of people aged 40 to 49 years old (21.28%). The type of relationship is with other family members (54.04%). The period of time that caregivers know the members listed on the network is up to 29 years (20.85%). The frequency of interaction is daily or they live together (60.00%), and the proximity is up to 15 minutes (34.04%).

For the intermediate or second circle, there was a predominance of females (52.43%), with ages between 20 and 29 (18.45%) and 40-49 years (18.45%) years old. The type of relationship is with other family members (71.84%). The period of time that caregivers know the members listed on the network is up to 19 years (32.04%). The frequency of interaction is daily or they live together (41.75%), and the proximity of the residences is up to 15 minutes (44.66%).

In the third circle, as in other circles, there was a predominance of female members (55.32%), aged between 0-09 years. The proximity of the residences is approximately 15 minutes, with the frequency of interaction being daily and the time of acquaintance is up to 10 years.

The functional aspects of social support were assessed using six different types of support: important things to confide; being soothed and stimulated in times of uncertainty, be respected, be careful in situations of illness; talk when sad, nervous or depressed , talk about their own health. In this analysis it is possible to identify how many members of the network receive and how many provide each kind of support (Table 1).

Comparing the social support network of the elderly and their caregivers, members provide more support to elderly, except for the kind of support that relates to confide important things, and receive more support from caregivers, with the exception of the types of support that concern being respected and talking about their own health.

Table 1. Percentage of members who give and receive social support of the elderly and their caregivers. Sao Carlos, 2010.

	Providing support members		Members who receive support	
	to the	to the	from the	From the
	elderly	caregiver	elderly	caregiver
	(%)	(%)	(%)	(%)
Reveal important things	15,4	21,6	20,0	37,4
Be reassured and encouraged in times of uncertainty	26,6	20,3	27,2	37,1
Be respected	92,5	73,8	89,9	76,6
Be cared for in situations of illness	33,4	24,2	60,6	61,0
Talk when sad, nervous or depressed	16,0	7,0	13,9	19,7
Talk about one's self health	31,9	17,4	27,6	24,2

Both the elderly and their caregivers report that they take care more than they receive care in situations of disease, however, caregivers report receiving this kind of support from a smaller number of members than the elderly, as well as providing such support to more members than to older members.

The analysis of the six categories of support revealed that, for all kinds of support, older people mostly provide and receive support of children, females, the age group between 30 and 39 years who are at a distance of max 15 minutes, and the frequency of interaction is daily or they even live together.

In the network of the elderly’s caregivers, members are usually female, age range 40 to 49 years, who are at a distance of no more than 15 minutes, and have a frequency of daily interaction or they live in the same house.

We can observe that the average total number of people reported by caregivers was statistically similar to that reported by the elderly. However, when the analysis focused on each circle, some differences were observed. In the first circle, the elderly mentioned a greater number of people than the caregivers, and in the third circle we observed the opposite. In both R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3787-94

groups the average number of people decreases as the interaction distances.

Recognizing that various issues relating to the operationalization of the concepts of social support network are still not fully resolved due to the characteristic of this multifaceted construction, and that studies using the Escort Diagram for evaluating social support network of elderly are scarce, it becomes difficult to compare the results.

Among the studies that used this instrument, a survey conducted in Rio Grande do Sul aimed to investigate the interference of social support and resilience in psychological disorders, neuroendocrine and immunologic chronic stress. The authors identified a total of 315 individuals in the network structure of caregivers and non-caregivers, with an average of 15.7 members per network.<sup>13</sup>

In the study of adaptation of the Escort Diagram on elderly people of Porto Alegre, the average by network members was made up of 10 individuals.<sup>10</sup>

Another study, conducted with elderly residents in the context of poverty in the State of São Paulo aimed to analyze the structure and function of social support networks for the elderly. The results revealed that the elderly subjects reported a total of 470 members of social networks, resulting in networks with an average of 12.4 people.<sup>14</sup>

Regarding the number of members per circle, the fact that the number of individuals decreases as the contact gets distant is as a trend in the studies cited above. Another aspect is the consistent predominance of female members in the networks of seniors and caregivers. Regarding the age of the members of the networks, this study differs from the studies cited above, where there is a growing trend of age as the contact gets distant with the interviewee, unlikely observed in this study.<sup>10,13,15</sup>

Regarding the functionality of social networks, it is observed that for both elderly people and their caregivers, networks are numerous, but few members offer or receive some kind of support. What is observed is that the quality or functionality of social support is more important for the adaptation of the elderly and their caregivers than the amount of network members and the frequency of contacts.

In this sense, the social support provided by the network is one of the most important resources that caregivers can use to deal with stress from the responsibilities of care for elderly relatives. Similarly, the elderly have this tool, since different social life and leisure activities can improve health status, in addition to being a protective factor for cognitive decline, because these aspects help keeping the elderly independent within his family, social and cultural background.<sup>16-17</sup>

CONCLUSION

Both the seniors and the caregivers evaluated reported belonging to social networks with similar characteristics. Caregivers provide more support than the elderly, and in both cases the social networks are numerous, however, few members play functional roles.

The use of social networks as a therapeutic resource must be considered in establishing the plan of care for the elderly, since the social support that the caregiver has to meet their needs influences their well-being and eases the tensions associated with the dependence of the elderly. Also, that satisfactory social networks for older people can improve their health condition, and consequently lessen the burden of care.

A new way of seeing this should be adopted to the elderly, family caregivers, and their social networks, to encourage the involvement of all social networks to positively exercise their role, R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3787-94

and thus the elder-caregiver relationship can be harmonious and balanced.

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